



## Caregiver Diversity

More than seven million people are informal caregivers – family members or friends who care for loved ones who are ill or have disabilities and live at home. There are wide variations in the conditions of those who are receiving help, the kinds of assistance needed, the level of caregiver burden, and the self-perceptions of caregivers. Caregivers come from all ethnic and racial backgrounds.

Asian American, African American, and Hispanic American households tend to be more involved in caregiving than the general population. In addition, the proportion of minority family members involved in caregiving is higher than those in non-minority families, particularly among adult children. The National Academy on an Aging Society found that adult children account for the largest proportion of caregivers. A partial profile of caregivers shows that:

- Spouses account for 28 percent of the caregivers of white elders, 20 percent among Hispanic Americans, and 15 percent among African American elders;
- More than 52 percent of Hispanic Americans receive care from adult children, while smaller proportions of African American and white elders receive help from their adult children; and
- African Americans are most likely to receive care from non-relatives.

### Working to Meet the Needs of Diverse Families

Diversity presents caregivers and the aging network with unique challenges. For example, due to differences in language and cultural beliefs and discrimination, minority families often have difficulty in or are reluctant to access information and services to which they are entitled. In addition, culture shapes both individual and group values and attitudes, including perceptions about what works and what doesn't work, what is helpful and what is not, what makes sense and what does not. Realizing this, the U.S. Administration on Aging (AoA) is striving to improve access to quality services by working with communities to offer culturally sensitive programs and services.

### National Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP), created by the Administration on Aging, and established via the reauthorization of the Older Americans Act by the 106th Congress, helps families sustain their efforts to care for older relatives with serious, chronic illnesses or disabilities. Under the Program, all states, working in partnership with area agencies on aging, offer five basic sets of services for family caregivers:

- Information about resources to help families in their caregiver roles;
- Assistance to families in locating services from a variety of private and voluntary agencies;
- Caregiver counseling, training, and peer support to help families cope with the emotional and physical stress of dealing with the disabling effects of a family member's chronic condition;
- Home-based respite care, adult day care centers, or weekend nursing home or residential (e.g., assisted living) community care; and
- Limited supplemental services to complement care provided by eligible caregivers to individuals needing help with at least two activities of daily living or requiring substantial supervision because of a cognitive or mental impairment.

Priority is given to older individuals with the greatest social and economic need and older individuals providing care and support to persons with mental retardation and related developmental disabilities.

## **Alzheimer's Disease Demonstration Grants to States Program (ADDGS)**

Mental health concerns are a priority for AoA. AoA supports a successful demonstration program designed to expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families, and caregivers. Projects demonstrate the effective coordination and use of existing public and private resources within states to enhance educational efforts and service delivery systems for this population. In June 2000, new grants were awarded to 16 states to develop models of care for persons with Alzheimer's disease and to improve the responsiveness of the home- and community-based care system for persons with dementia. Projects are targeted to hard-to-reach populations including ethnic minorities and low-income and/or rural populations with Alzheimer's disease.

## **Future Challenges**

Diversity presents everyone – especially those involved in the aging network – with a unique set of challenges and opportunities. A specific challenge involves providing critical information to minority caregivers, some of whom may speak languages other than English. Projected increases in the minority population, coupled with distinct, varying cultures have ramifications for caregiver support programs. Those involved in providing services to diverse caregivers must become familiar with racial, cultural, and ethnicity issues and how they affect caregiver beliefs and practices.

## **Cultural Competency Check**

Our aim must be to provide the right services in the right ways to the right persons at the right time in the right settings. To help accomplish these goals, AoA offers the following:

- **People:** Community and consumer participation is key. Find community members who are respected and valued. Maximize investment by using volunteers. Train the front line because a culturally aware staff is more effective.
- **Places:** Go to your target audience. Identify places that are logical sites for the groups you want to reach. Be creative.
- **Process:** Update communications styles. Use sensitivity. Seek greater knowledge. Find alternatives to written communication. Use materials reflective of the community.
- **Pathways:** Values and attitudes matter. Promote mutual respect. Employ a client-centered perspective. Recognize that belief systems influence behavior and community involvement.

In a collaborative environment, AoA is confident we can meet the challenges and maximize the opportunities posed by population diversity in the 21st century.

Working in close partnership with its sister agencies in the U.S. Department of Health and Human Services, the AoA is the official Federal agency dedicated to policy development, planning and the delivery of supportive home and community-based services to older persons and their caregivers. The AoA works through the national aging network of 57 State Units on Aging, 655 Area Agencies on Aging, 225 Tribal and Native organizations representing 300 American Indian and Alaska Native Tribal organizations, and two organizations serving Native Hawaiians, plus thousands of service providers, adult care centers, caregivers, and volunteers. For more information about the AoA, please contact:

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